

Consent, Ebola, and the fine line between collaboration and exploitation in research conducted during public health emergencies

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THANK YOU!

- Lisa Schwartz PhD, Ani Chénier, MA, John Pringle, PhD, Matthew Hunt PhD, Oumou Bah-Sow, MD, PhD, Sékou Kouyaté, MA, Sonya De Laat, PhD, Gautham Krishnaraj MSc, Carrie Bernard, MD, Lynda Redwood-Campbell, MD, FCFP, DTM&H, MPH, Laurie Elit, MD, MSc FRCS
- Colleagues (many in room)
- **Study participants**
- \$ Funders \$ ☺ ☺ : R2HC & CIHR

The weight of consent (structure of talk)

1. Overview of project and 'data' that is pt of departure for this talk
2. Slowing down, really listening to and thinking with West African study participants' social rationales for participation in research
3. Consent and (mis)recognition

Part I:

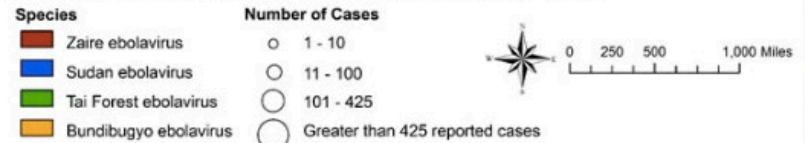
Ebola and one Canada-West Africa
R2HC-funded project

The West Africa Ebola Virus Disease epidemic

	Reported cases	Deaths
Guinea	3,814	3,956
Liberia	10,678	3,956
Sierra Leone	14,124	4,810



EBOLAVIRUS OUTBREAKS BY SPECIES AND SIZE, 1976 - 2017



Perceptions and moral experiences of EVD research

Humanitarian Healthcare Ethics, Guinean National Health Research Ethics Board, R2HC



Density of physicians per 1000



Density of physicians per 1000





Perceptions and Moral Experiences of Ebola Research

Study objectives:

- 1) To deepen understanding of challenges and strategies for the ethical conduct of research during public health emergencies, with particular attention to the rolling out of clinical trials
- 2) To learn how Ebola quarantine and isolation disease control measures, such as voluntary consent, interacted with ethical standards of research interventions in Sierra Leone, Guinea, Liberia
- 3) To add evidence to existing recommendations for the ethical conduct of research in public health emergencies



Contents lists available at [ScienceDirect](#)

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

The *oughtness of care*: Fear, stress, and caregiving during the 2000–2001 Ebola outbreak in Gulu, Uganda

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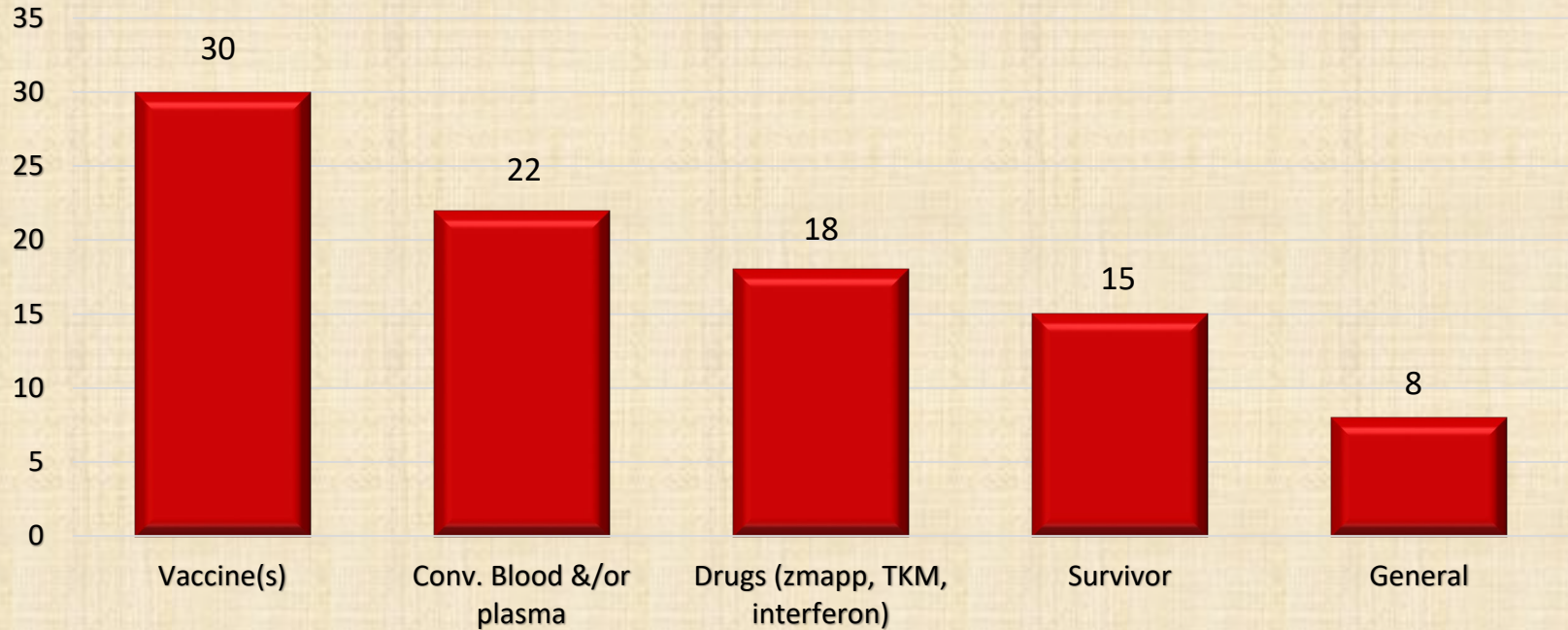
Who did we interview?

-65 men, 43 women

-91% West African



Research studies discussed by our participants



KEY QUESTIONS

- **“What motivated you to support, participate in, or decline participation in this research?”**
- **“Did anything make you uncomfortable or leave you feeling troubled?”**
- **“What was done well?”**





(Antierens & Frontières, 2014)

***“Doctor, do whatever you want to do,
as long as I get better.”***

(P72)

“...those taking consent should exercise more time. Which unfortunately was not the case in the Ebola business...in that kind of situation, you just want to talk less and start the treatment.”
(P80)



Therapeutic optimism framing recruitment as the only ethical objective

- “You need to cajole them”



Tx Misconception - vaccine

“They told us that if we got vaccinated, even if Ebola is in this area, we will be sheltered. That we will never again be able to get Ebola. ”

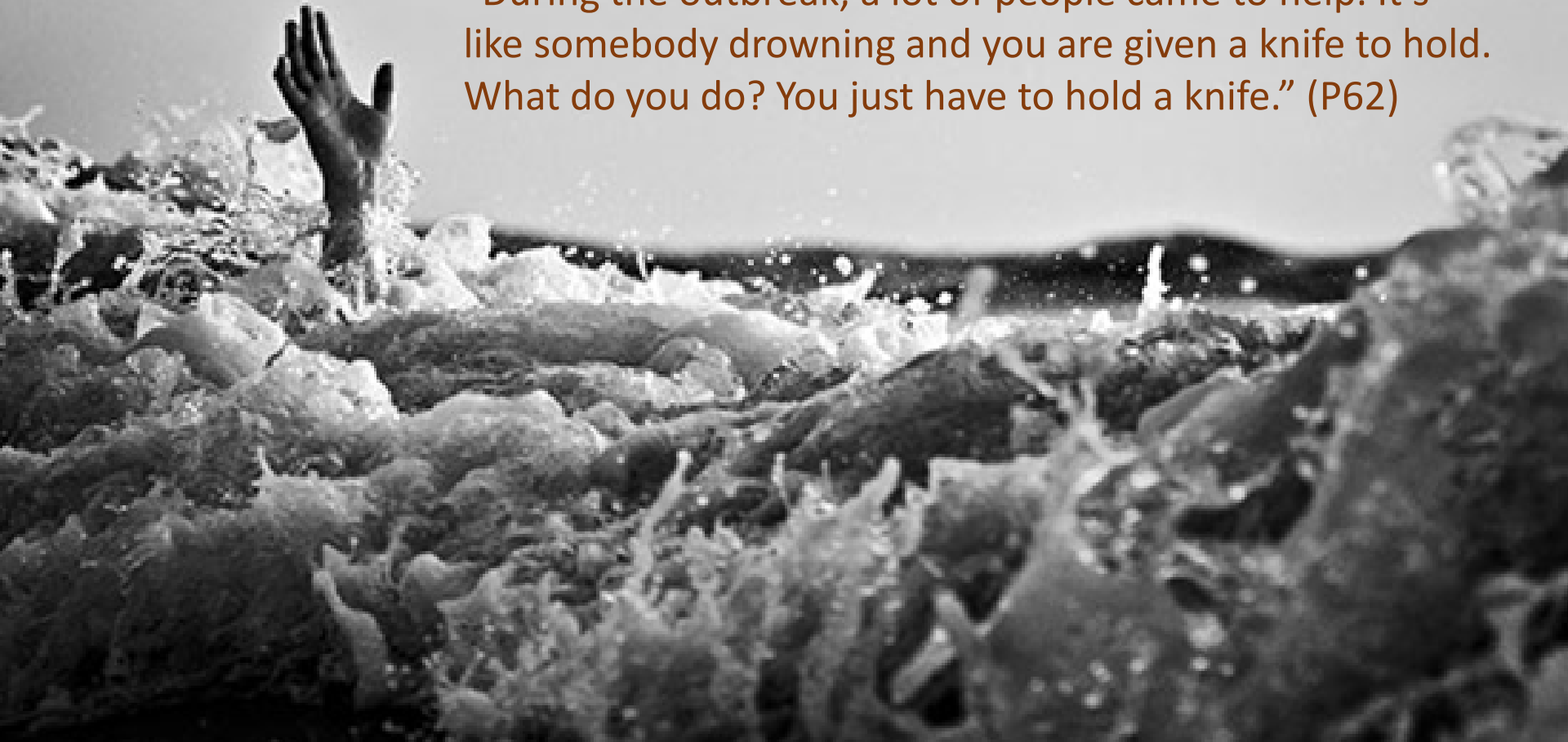


NEED

**Access to
otherwise
inaccessible
healthcare
services**



“During the outbreak, a lot of people came to help. It’s like somebody drowning and you are given a knife to hold. What do you do? You just have to hold a knife.” (P62)



INADEQUATE COMMUNICATIONS

- Trials started before final ethics approval
- Lack of clear info
- Survivors wanted to be and not consulted before studies approved
- Lack of post-trial communication = feeling used

Tx misconception

- Ethical / practical problem b/c
 - Decision-making based in delusion/mis-information
 - Can result in disappointment and loss of trust

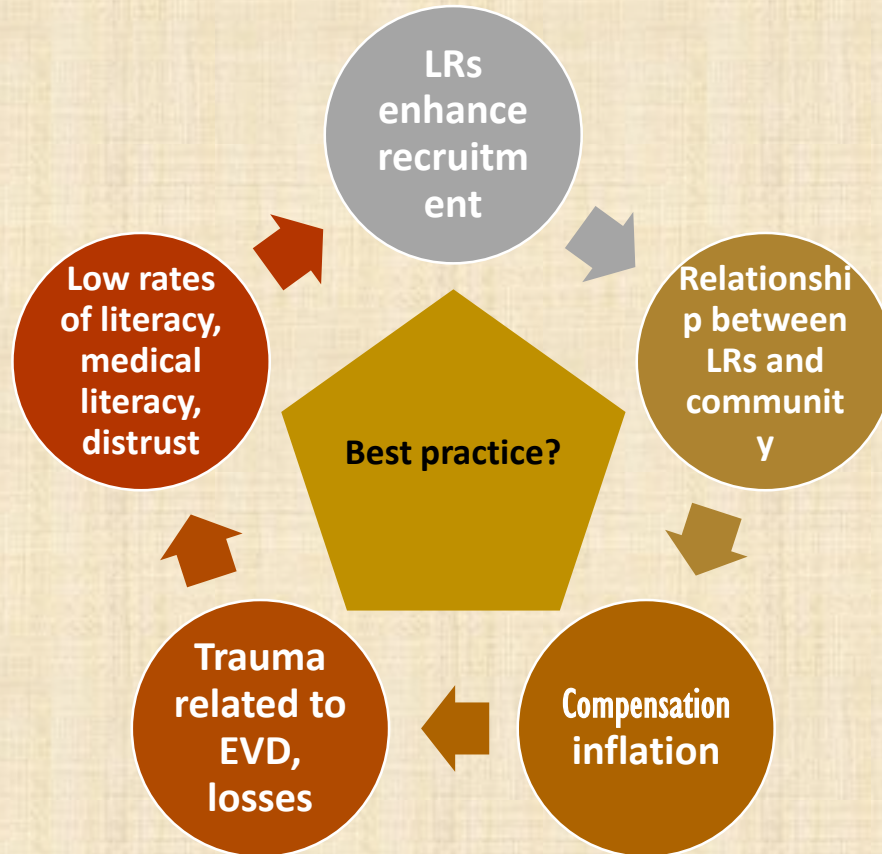
“Consent or collaboration misconception”

Harm –

disappointment, loss of trust feeling objectified and misled –

comes from entering research with (mi)sconception that this is collaboration

Consent complexities



Part II:

Social connection rationales animating participation
in research

In ETU: “Emmanuel”

-Nurse recognizes family name: her family is from the same village

“On the outside, I know you people have heard a lot of rumours, that the drugs that they offer you are going to kill you. You’re going to die. So I beg you, this is the drug that we give. It is an experimental drug that we are giving. But we know it is saving people. It is helping people to regain their strength, to regain their life. ... *So take it in.*”

- Nurse: “I am not here to harm you, I’m not here to kill you. I am your relative. I am your sister. So take it in. So I said OK, and I took it in.”

“...since I am an Ebola survivor, I know what was going on in the ETC, I could not just stay there like that, standing idly by *with my arms crossed*, refusing to give life to other people who were still suffering.”

(P11)

...I had to contribute, in my way, to researching the disease.

(P34)

I know what I've undergone, I don't want this disease affect any other citizens.

(P55)

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The Ebola vaccine we dared to dream of is here

Jeremy Farrar

Mon 3 Aug 2015 02:00 EDT

8,236 185

4 'More than 7,600 people in Guinea have received a vaccine against the Ebola virus.' Photograph: David Cole/Alamy

A success rate of 100% in trials is spectacular. There is no excuse for inertia on other diseases now



For more than a year and a half, three of the world's poorest countries have struggled against the most devastating Ebola epidemic in human history. Containing this unprecedented outbreak would have been a huge challenge for Guinea, Liberia and Sierra Leone under any conditions. But the scale of the task was far greater because of the absence of the most effective possible defence: a vaccine.

That may all be about to change. I normally like to avoid superlatives when describing the interim results of a medical trial, but it is difficult to talk about the report of the experimental Ebola vaccine in the *Lancet* as being anything less than spectacular. More than 7,600 people in Guinea have received the vaccine, known as rVSV-ZEBOV, in a study that targeted people from communities with cases of Ebola. None who received it immediately has so far contracted the virus. That's an efficacy of 100%. And not only has it been shown to be so effective, it has also been well tolerated, with few side effects. This is rare for vaccines such as this one that contain a live virus, and it's something to be thankful for.

It is in fact incredibly unusual for any vaccine to show such efficacy, and so swiftly, too. For comparison, not long ago the results of trials for new malaria and dengue fever vaccines showed just how challenging development is. While they were promising, their effectiveness was much more limited.

These Ebola results mean it is much more likely that we can fight back against future outbreaks. The procedure would be to vaccinate a ring around known cases. That way, further infections can be prevented. In fact, this strategy should now play an important role in bringing the present epidemic to an end fast.

Ebola vaccine trial proves 100%

most viewed in US

- Dangerous, growing, yet unnoticed: the rise of America's white gangs
- It feels like we're all dying slowly: Venezuela's doctors losing hope
- Ex-Trump aide Paul Manafort approved black ops to help Ukraine president
- The demise of the nation

"It's got to be altruism," he told The Globe and Mail.



Hundreds of Nova Scotians volunteer for Ebola vaccine trial



Dr. Scott Halperin, seen at the IWK Health Centre in Halifax, will be conducting the first trials of Canada's Ebola vaccine.

Ebola and Learning Lessons from Moral Failures: Who Cares about Ethics?

Maxwell J. Smith*, University of Toronto
Ross E.G. Upshur, University of Toronto

Part III:


(Mis)interpreting Consent & (Non)recognition

Nancy Fraser 2001, p. 6

“Recognition or redistribution?”

- Recognition is fundamental to any redistribution
- (Mis)recognition of those with less resources as not our peers at core of why and how inequities persist
- Recognition is fundamental to the sharing of power and to transformative politics/policy

rec·og·ni·tion

/ˌrekəgˈniʃ(ə)n/ 

noun


noun: **recognition**; plural noun: **recognitions**

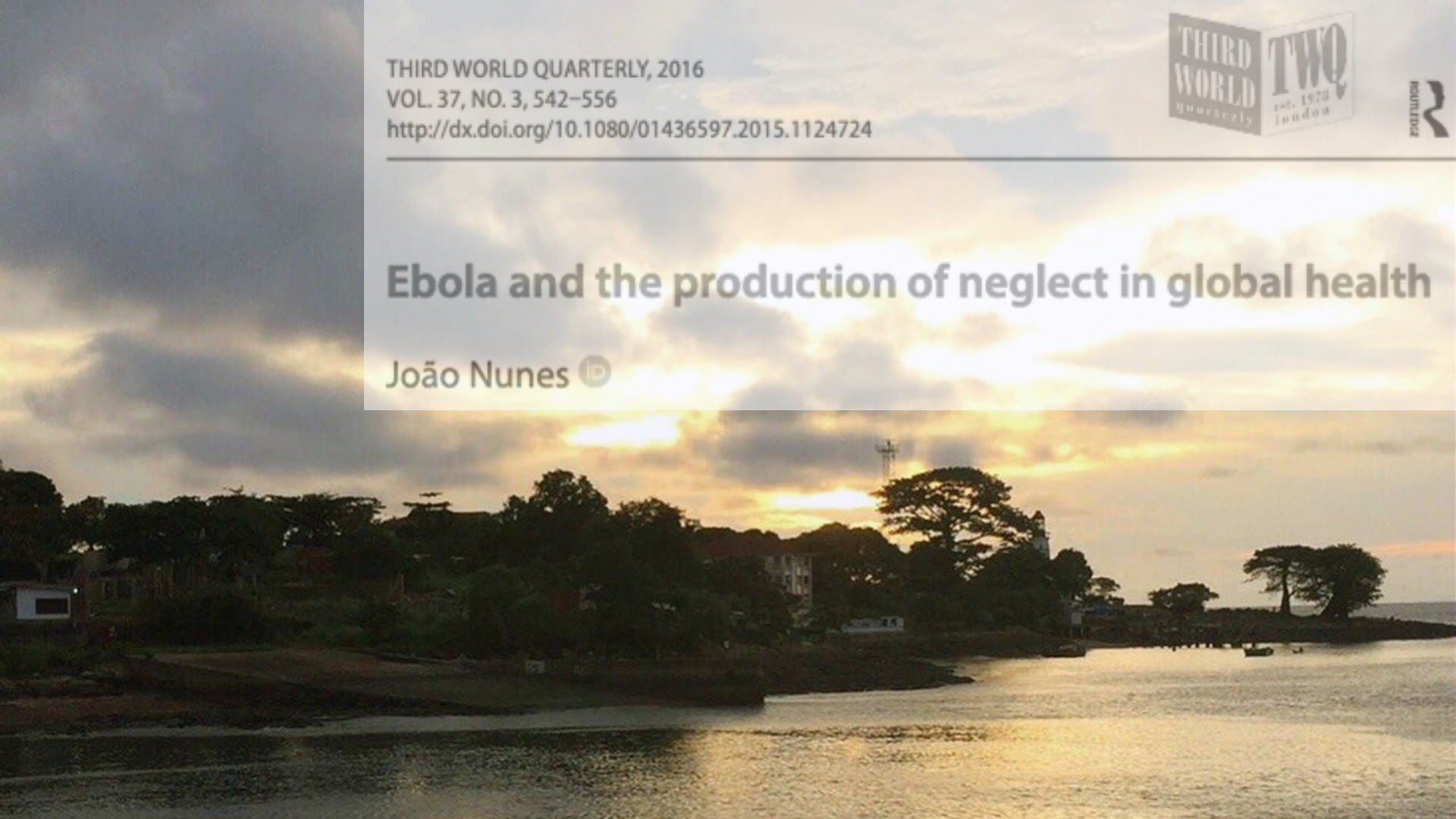
1. identification of someone or something or person from previous encounters or knowledge.
2. acknowledgment of something's existence, validity, or legality.
 - appreciation or acclaim for an achievement, service, or ability.
 - formal acknowledgment by a country that another political entity fulfills the conditions of statehood and is eligible to be dealt with as a member of the international community.

THIRD WORLD QUARTERLY, 2016
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<http://dx.doi.org/10.1080/01436597.2015.1124724>



Ebola and the production of neglect in global health

João Nunes 



“Systematic mis-recognition has led to forgetting or to the imposition of narratives that do not correspond to actual lived experiences. This in turn has had an impact upon how injustices and suffering are dealt with.”

(p. 542)

rec·og·ni·tion

/ˌrekəɡˈniʃ(ə)n/

1. identification of someone or something or person from previous encounters or knowledge.

"he stared at her, but there was no sign of recognition on his face"

Thank you!
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 	Participants' Perceptions of Ebola Research Report to participants
<p>Report prepared by:</p> <p>Dr. Elysée Nouvet Professor, School of Health Studies, Western University (Canada) et McMaster University (Canada)</p> <p>Ani Chénier Research Coordinator Humanitarian Health Ethics Research Group, McMaster University (Canada)</p> <p>Sékou Kouyaté Research Assistant</p>	<p>What is the purpose of this report?</p> <p>In 2016, we launched the "Perceptions and moral experiences of research conducted during the West Africa Ebola outbreak" study (the "Perceptions" Study). This study seeks to better understand the practical and ethical issues of research conducted in public health crisis situations. To this end, we conducted 108 individual interviews in Guinea, Liberia and Sierra Leone with 3 categories of people: (1) participants in clinical trials and other studies conducted between 2014-6; (2) researchers, and; (3) African and foreign leaders who supported or evaluated these studies (e.g.: government representatives, scientific committee members).</p> <p>This report looks at category (1), people who participated in research, and answers the following questions:</p> <ul style="list-style-type: none">• How did the people who participated in research conducted during the